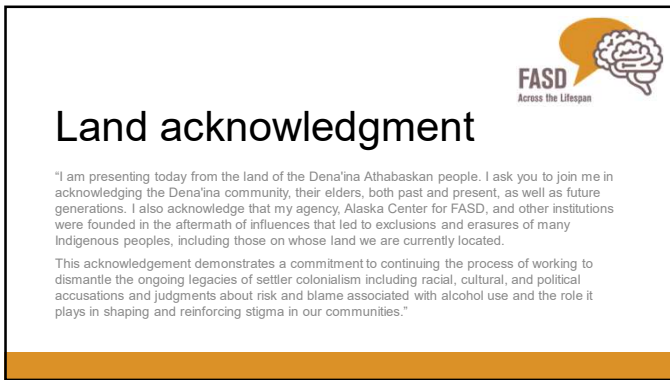




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Marilyn Pierce-Bulger
 MN, FNP-BC, CNM (APRN)

Interim President, Board of Directors, Alaska Center for FASD

Marilyn@alaskacenterforfasd.org




Alaska Center for
Fetal
Alcohol
Spectrum
Disorders

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Session Objectives

By the end of this session, participants will:


- Recognize changing patterns of alcohol consumption in the U.S. & currently recommended effective FASD prevention strategies
- Identify how prenatal alcohol exposure can impact a fetus/child
- Discuss FASD diagnosis criteria, evaluation process, and Alaskan resources



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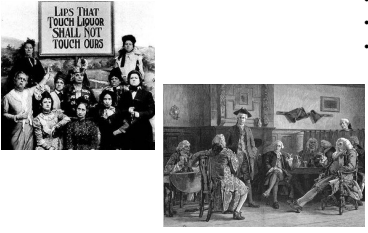
Alcohol Use in the U.S. & Alaska

Information you may not know...but we all need to think about!



6

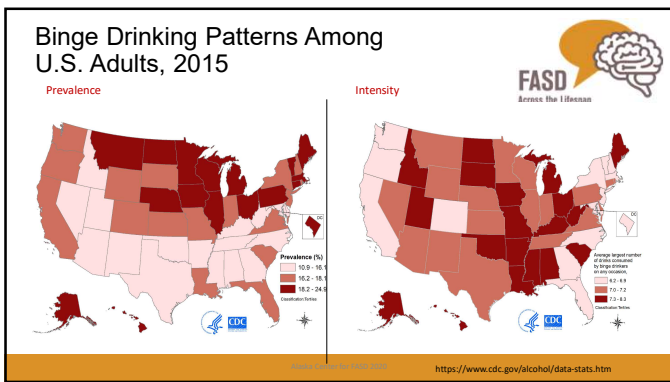
Long History of Alcohol Use in American culture



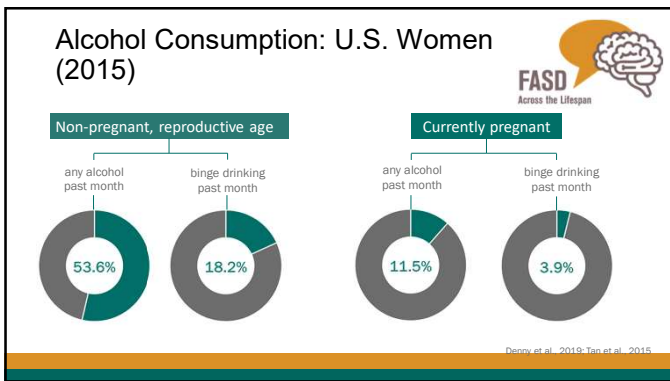
FASD
Across the Lifespan

- Payment for services
- Temperance Movement, Prohibition
- Current role- 'social glue' used for:
 - Celebrations
 - Sports & social events
 - Memorials
 - "Nights out" to relax & socialize with our friends
 - Teen 'rites of passage'
 - Self-medication when it is too difficult or expensive to access mental health services
- Alcohol sales & use has increased since COVID onset

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PREVENTION AUDIT (U.S.): Alcohol Use Disorders Identification Test


Instructions: Alcohol can affect your health, medications, and treatment, so we ask patients the following questions. Your answers will remain confidential. Place an X in one box to answer each question. Think about your drinking in the past year. A drink = one beer, one small glass of wine (5 oz.), or one mixed drink that contains one shot (1.5 oz.) of spirits.

Questions	0	1	2	3	4	5	6	Score
1. How often do you have a drink containing alcohol?	Never	Less than monthly	Monthly	Weekly	2-3 times a week	4-6 times a week	Daily	
2. How many drinks containing alcohol do you have on a typical day when you are drinking?	1	2	3	4	5-6	7-9	10 or more	
3. How often do you have X or more drinks on one occasion? (5 for men under age 65; 4 men aged 65 or older and all women)	Never	Less than monthly	Monthly	Weekly	2-3 times a week	4-6 times a week	Daily	
TOTAL (1-3)								
4. How often during the last year have you found that you were not able to stop drinking once you started?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
5. How often during the last year have you failed to do what was normally expected of you because of drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
6. How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
7. How often during the last year have you had a feeling of guilt or remorse after drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
8. How often during the last year have you been unable to remember what happened the night before because of your drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily			
9. Have you or someone else been injured because of your drinking?	No		Yes, but not in the last year		Yes, during the last year			
10. Has a relative, friend, doctor, or other health care worker been concerned about your drinking or suggested you cut down?	No		Yes, but not in the last year		Yes, during the last year			
TOTAL (4-10)								

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New efforts - 'sober curious' movement

- Alcohol is only substance of abuse we have to *explain why we don't use it...*
- Followers interested in personal functional & health benefits
 - Improved sleep
 - Weight loss
 - Better liver function
 - Improved cognition
- Maintain 'social' atmosphere without alcoholic beverages



https://www.washingtonpost.com/facts/the-parenting/mothers-are-drinking-more-than-ever-but-the-sober-curious-movement-challenges-wine-mom-culture/2019/07/05/93351576-90ac-11e9-b27f-e9294273670_story.html



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Fetal Alcohol Spectrum Disorders

Often not on medical and mental health providers' radar...

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Factors that are *Increasing* FASD Prevalence

- High unintended pregnancy rates
AND
- High rates of binge pattern use and continued drinking in pregnancy
AND
- Providers missing opportunities to talk about the risks (stigma or ignorance)
EQUALS
- Increased risk of *rising* numbers of fetal alcohol spectrum disorders (FASDs) in the U.S.

Photos courtesy of the University of Louisville FASD clinic-Weiskopf/ing Center, Child Evaluation Center and the FASD Southeast Regional Training Center
www.FASDSoutheast.org

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FASD is more common than we think



U.S. estimate is 5% (1 in 20) school age children may have an FASD

~47,860 people have **Fetal Alcohol Spectrum Disorders (FASD)** in Alaska, including 2,950 who have **Fetal Alcohol Syndrome (FAS)**.

For those with **FAS in Alaska**, the estimated annual cost of services, including home and residential care associated with mental disability, medical equipment, special education, and lost productivity, is **\$35 million**

47,860/731,545 = 6.5% of Alaskans have FASD (1 in 15)


Based on US & international data, a higher prevalence (6.0-16.9%) rate is found among children in:
Foster care
Juvenile justice systems

Elizabeth age 5 photo used with permission

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Prevalence of FASDs Compared to Other Developmental Disabilities




Birth Defect	Prevalence (in US as of May 2014)
Spina bifida	1/1000 births
Down Syndrome	1.2/1000 births
Cleft lip +/- palate	1.2/1000 births
Fetal Alcohol Syndrome (FAS)	6 – 9/1000 school age children
Autism	12.4 – 14/1000 school age children
All FASDs	24 – 48/1000 school age children

Table from <http://pediatrics.appublications.org/content/early/2014/10/21/peds.2013.3319>

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FASD Research Funding: Lagging Resources



Condition	Prevalence in U.S.	2018 NIH Spending*
Down Syndrome	1 in 700	\$60 million
Cerebral Palsy	1 in 250	\$26 million
Epilepsy	1.2 in 100	\$184 million
Autism	1 in 59	\$281 million
Fetal Alcohol Spectrum Disorders (FASD)	1 in 20	\$34 million


NOFAS Michigan www.mcfares.org

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Stigma contributes to decisions about discussing alcohol use, especially during pregnancy.

Stigma increases patient fears of being judged or devalued by others, especially a healthcare provider.




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Laurie shares her perspective on stigma...

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Historical context matters...




Think about the over-representation of AN/Al or African American clients in the OCS system

- Each has been subjected to significant historical, multi-generational trauma and disadvantages that are passed down repeatedly unless active efforts were made to 'break the cycle'
- Alcohol & substance misuse are *symptoms* of the problem, not just 'the problem' AND can reflect a failure of access to behavioral health/substance treatment programs, low SES conditions, etc.
- Maladaptive coping skills are passed down via generations (children learn what they live...) and *may* be related to brain damage experienced by the parents themselves

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Racism and Implicit Bias...



"Racism is a system of structuring opportunity and assigning value based on the social interpretation of how one looks that unfairly disadvantages some individuals and communities, unfairly advantages other individuals and communities, and saps the strength of the whole society through the waste of human resources".

Implicit bias is attitudes, stereotypes & beliefs... It is *not intentional* but can still impact how we judge others based on many factors (race, culture, ability, gender, language).

"The system is not broken, it is working the way it was designed to work..."

Ruth Richardson, JD (Minnesota)
NOFAS Summit speaker 9/23/20

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Prenatal Alcohol Effects on Fetus



Much more than you may realize...

© 2019 FASD Across the Lifespan

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Many Factors Influence the Effect of Alcohol on a Fetus

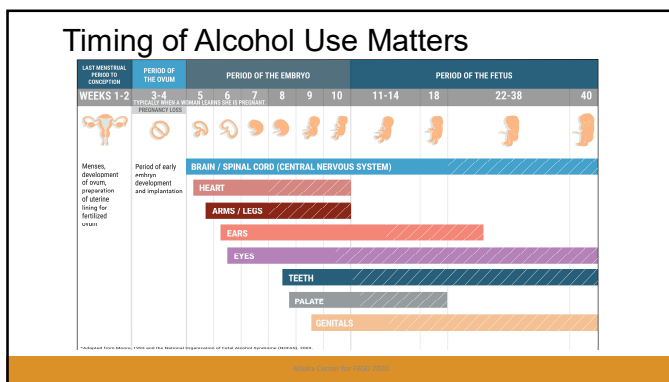
Maternal

- *Genetics
- *Epigenetics
- *Stress
- *Micronutrients
- *Age/Parity
- *Other substances/meds

Fetal

- *Genetics
- *Epigenetics
- *Windows of development
- *Dose and timing of alcohol


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How much alcohol is 'safe'?

- Fetus has little to no ability to metabolize alcohol
 - Placenta is a 'sieve' & fetal level may be higher than mother's
 - Relies on mother to remove alcohol from system
 - Accumulates in amniotic fluid (where fetus is re-exposed)
- **Binge pattern known to be the worst**
 - Unpredictable outcome with 'light to moderate drinking' patterns
 - May not follow a simple linear dose/response pattern



Chasnoff, 2010; Feldman et al., 2012

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FASD Diagnosis Criteria & Process

It's complicated...but long-term research tells us what to look for...

www.fasd.org | 1-800-458-3437

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FASDs are vastly under-recognized

- Only 11% are diagnosed by age 6
- 80-85% of children are missed or have been misdiagnosed*
- **Stigma and bias**
 - Provider reluctance to ask
 - Mother reluctance to report
- FASD 'not on radar' of providers
 - Birth history often unknown
 - Lack of adequately sensitive and specific biomarkers
- Most have no physical characteristics
- Recent DSM-5 (psychology handbook) inclusion

www.fasd.org | 1-800-458-3437 *Chenoff et al. 2015

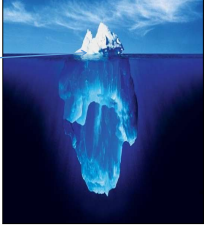
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FASD presents along a continuum

Behavioral, cognitive, neurological, and physical symptoms

- Fetal alcohol syndrome (FAS)
- Partial fetal alcohol syndrome (pFAS)
- Static Encephalopathy
- Neurobehavioral Disorder
- Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE) in Appendix of DSM-V



www.fasd.org | 1-800-458-3437

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Components of an FASD Diagnosis:

- Growth
- Facial Features
- Brain impact – behavioral, cognitive, neurological and psychological
- Confirmation of alcohol exposure

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4-Digit Diagnostic Code Grid

One Example of FAS: 3 4 4 4

significant	significant	definite	4	X	X	X	4	high risk
moderate	moderate	probable	3	X			3	some risk
mild	mild	possible	2				2	unknown
none	none	unlikely	1				1	no risk
Growth Deficiency	FAS Facial Features	Brain Dysfunction		Oral-Facial-Speech	Alcohol			Occupational Alcohol

Lip-Philtrum Guide 1

For use as a guide to help in a complete clinical history. History includes: color, shape, texture, size, etc. Square shows length of philtrum (range is correct).

Lip-Philtrum Guide 2

For use as a guide to help in a complete clinical history. History includes: color, shape, texture, size, etc. Square shows length of philtrum (range is correct).

Copyright Image used with permission, Dr. Susan Kelley, University of Washington FASD-PN 2016

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Subtle to Obvious Problems

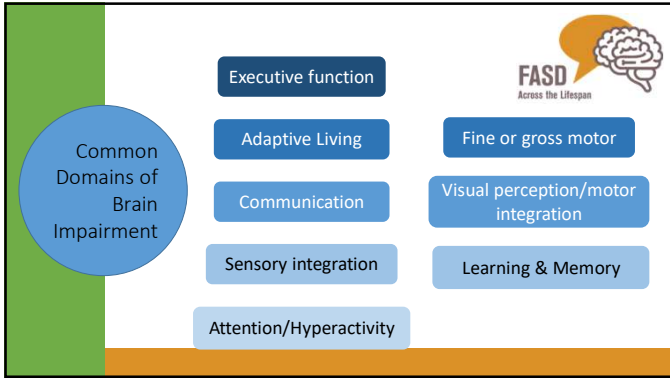
Dr. K.L. Jones, Department of Pediatrics, University Hospital, University of California at San Diego. (Reproduced by permission of Dr. Jones).

Alcohol can cause varied physical malformations:

- Maxillary hypoplasia
- Epicantal folds
- Palmar flexion crease (hockey stick)
- Cardiac anomalies
- Joint disability
- Overlapping fingers
- Ptosis
- Hypoplastic nails
- Pectus deformities
- Microcephaly & other structural alterations in CNS
- Palate alterations & Cleft lip
- Vertebral and rib anomalies

© 2014 Susan Jones, University of Washington FASD-PN 2016

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When misunderstood or needs are unmet, *behavioral* symptoms are common...

- Tires easily,
- Over activity,
- Irritability, tantrums
- Anxious &/or depressed
- Lonely, isolated
- Easily manipulated by others
- Self-harming behaviors
- Shuts down, flat affect
- Fearful, withdrawn
- Avoidant, runs away
- Frustrated short, fuse, angry
- Aggressiveness
- Destructive
- Talks back, argumentative
- Remarkable sexual activity

• Diane Malbin, FASCEETS

FASD Across the Lifespan

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Pros and Cons of Getting an FASD Diagnosis

Pros

- Professionals who understand that alcohol is part of the prenatal story can interpret their test findings through that lens
- The individual or caregiver (no matter the age) has information that helps them understand the unique brain function
- Can help to prevent secondary behaviors if receive appropriate interventions & understanding care



Cons

- Diagnosis difficult to make if do not have confirmed alcohol story
- Those who have trauma may have symptoms that overlap with FASD
- Some think that FASD is a 'label' that stigmatizes an individual
- It is hard work for the caregiver/individual to go through a comprehensive process
- The final diagnosis may not be one that meets criteria for DD or other eligibility

FASD Across the Lifespan


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Adult self- advocate
GINA shares her thoughts...

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FASD Diagnostic Teams in Alaska



- *State-funded* teams in Fairbanks, Kenai/Soldotna, Wasilla during 2020
 - Many issues surrounding survival of teams, NOT new problem
- ANTHC/Southcentral Foundation and Mat-Su (Ptarmigan Connections) have neurodevelopmental clinic model embedded in a health care clinic or system
 - Tiered system: ETOH hx-FASD clinic, Autism, or ND general clinic- planned statewide reach for AN/AI kids
- Multidisciplinary team approach the best to discern how brain built differently
 - UW model difficult for small communities to support-medical, psychology, SLP, OT, Coordinator
- Efforts underway for new FASD diagnosis clinic access at Providence Neuroscience Clinic, Sitka, Ketchikan, & Nome during 2021...stay tuned!

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System issues continue despite over 30 years of FASD-related efforts in Alaska:



- Medical, nursing, SLP, OT, Psych, education providers trained in AK *BUT FASD is not generally part of their curriculum** so many providers are still unformed and *may do harm*
- *Misdiagnosis not unusual (autism, ADHD, bipolar disorder)*
- *Wait lists delay care and many areas do not have services at all*
- *Those who do not get a diagnosis and/or services are overrepresented in our behavioral health, SPED, criminal justice, OCS, and other systems- we pay on the back end because we don't pay on the front end...*

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Let's create statewide understanding & support



Alaska Center for Fetal Alcohol Spectrum Disorders


FASDx Services followed families who've received diagnoses & as result in 2017 a non-profit the **Alaska Center for FASD** was created to address the lack of support & to help those who are impacted by FASD so they do *not feel alone in their disability*

<https://alaskacenterforfasd.org/>

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In Summary



- Alcohol is a common substance, heavy use has been normalized, and potential impacts have been minimized
- Women who drink & those with FASD are stigmatized and misunderstood by professionals, communities, and caregivers/families
- Early identification/intervention is difficult as presentation/symptoms emerge over time & may be misdiagnosed
- FASD diagnosis is the beginning of understanding/supports, not the 'end point'.
- It is not a 'label' it is *an explanation*....that can support the individual to understand themselves AND learn how to self-advocate for what helps them succeed

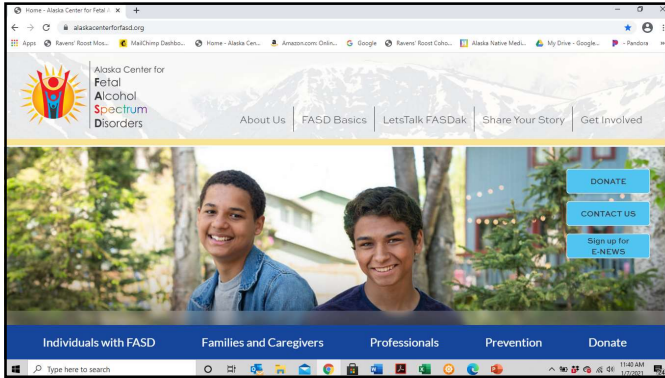
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Resources

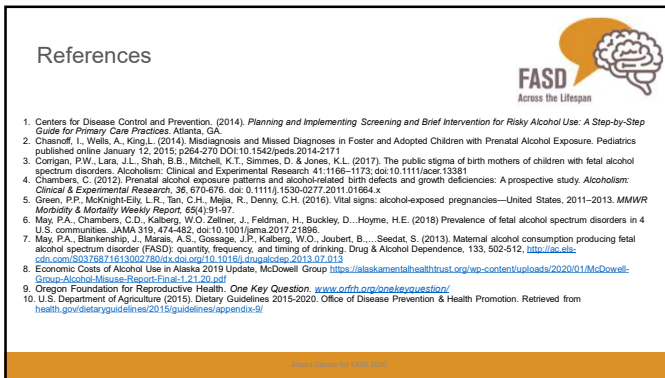


- <https://www.nofas.org/> NOFAS has fact sheets, videos, Circle of Hope online support for birth moms
- <http://www.alaskacenterforfasd.org/> Alaska Center for FASD, non-profit created to support prevention efforts and families & individuals with FASD; website has information for individuals w FASD, their caregivers, and professionals
- <https://www.acrf.org/> Alaska Center for Resource Families will have this series of webinars on their website, launching in Sept 2021

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